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Growing Up in the Era of AIDS: The Well-Being of Children Affected and Infected by HIV/AIDS in Sub-Saharan Africa

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1. Introduction

Children may be affected by HIV/AIDS in numerous ways. When parents fall ill from HIV-related infections, household income falls or is diverted to medical expenses, food insecurity increases and children may have to drop out of school to take on care responsibilities. When parents die, children are orphaned and, besides coping with grief at the loss of their mother or father, they face new care arrangements which may involve separation from siblings and migration to a new location. Most of the children who are orphaned and made vulnerable by HIV/AIDS live in sub-Saharan Africa. UNAIDS (2010, p. 180) estimates that 67.6 percent of people living with HIV globally are found in sub-Saharan Africa, but nearly 90 percent of all children orphaned by AIDS - 12.1 million children - live in sub-Saharan Africa (UNAIDS, 2010, p. 186).

Children may be infected with HIV through mother to child transmission (MTCT) during pregnancy, at birth or through breast milk. Such paediatric AIDS is increasingly being discovered and treated through programmes to prevent MTCT (PMTCT). Adolescents may be living with HIV: they may have been infected by MTCT and survived through childhood or they may have been infected through sexual intercourse, sadly often through being raped. UNICEF et al. (2010, p. 15) call this a "hidden epidemic" because many adolescents living with HIV do not know they are infected, they have never been tested and do not access treatment. UNICEF et al. (2010, p. 41) estimate that in 2009 92 percent of children (under the age of 15) who were living with HIV were in sub-Saharan Africa (nearly 2 million children) and 70 percent of these were found in East and southern Africa. In sub-Saharan Africa in 2009 only 26 percent of children deemed to require antiretroviral treatment (ART) were estimated to receive it (UNICEF, et al., 2010, p. 41).

Sub-Saharan Africa clearly bears a disproportionate burden when it comes to the effects of HIV/AIDS, particularly on children. This chapter gives an overview of the impact of HIV/AIDS on the well-being of affected and infected children, and reviews the responses at community, national and international levels.

2. Children affected by HIV/AIDS

Various terms have been used to describe children who have been affected by HIV/AIDS. Early studies on the social impact of HIV/AIDS used the concept of 'AIDS orphan' defined

as a child below the age of 18 who has lost one or both parents to HIV/AIDS. In 2004, UNICEF et al. (2004, pp. 3-4) commented on the fact that there are many ways in which HIV/AIDS can make children vulnerable, for example, children whose parents were ill, but had not yet died, were already vulnerable; hence the term 'orphans and vulnerable children' (OVC) was preferred (Sherr et al., 2008; UNICEF, et al., 2004). However, AIDS is not the only cause of orphaning so the concept of OVC included children orphaned by other causes. Labelling as orphans children who have lost one parent and continue to live with the surviving parent equates their vulnerability with that of double orphans whose lived experience may be very different. Meintjies & Giese (2006) are highly critical of the focus, particularly by international agencies such as UNICEF, on the term 'orphan' when it is used without clear specification of age and the details of which parent(s) died. The term 'children affected by HIV/AIDS' includes children orphaned by AIDS, children who are vulnerable because their parents are ill with HIV/AIDS-related infections or who experience HIV-related poverty, food insecurity or psychosocial challenges. It excludes children orphaned by causes other than HIV/AIDS.

2.1 Caregiving situation

Many children whose parents are HIV positive experience the prolonged illness and eventual death of their parents from AIDS-related infections. Children often take on significant care responsibilities such as preparing food, cleaning, other household chores as well as providing physical and moral support for the ill parent (Bauman et al., 2006). Skovdal and colleagues (2009, 2010) have studied the impact on children's well-being when they care for sick parents and caregivers. Prolonged illness leads to a reduction in household income and food production, depletion of savings due to expenditure on health services (van Blerk & Ansell, 2007) and children are frequently obliged to try and earn some cash and produce food in addition to taking care of their sick parents (Skovdal, 2010; Skovdal & Ogutu, 2009; Skovdal et al., 2009). When children affected by HIV/AIDS take on productive and reproductive tasks, this often involves dropping out of school. The roll-out of antiretroviral treatment (ART) in the past decade has significantly reduced death from AIDS (Mwagomba et al., 2010; Reniers et al., 2009), but as there is not yet full coverage for all those who need ART, some children continue to experience parental illness and death.

In many parts of Africa it is customary for children to stay for some time with adults other than their biological parents (usually members of the extended family), for example a child from a rural area might live with a relative in an urban area to access a level of schooling unavailable in the rural area. Such 'voluntary' fostering was seen as mutually beneficial: the child would get an education and the foster caregiver would receive agricultural products from the rural area and help with household chores (Madhavan, 2004). AIDS has introduced 'crisis' fostering where adult relatives feel obliged to take on children whose parents have died; such fostering lacks the element of reciprocity and is instead "a normative social obligation" (Goody, 1982, cited in Madhavan, 2004, p. 1444). While many children receive good care from their new caregivers, others may experience varying degrees of injustice and abuse. Several studies document how orphaned children may have to do a disproportionate amount of household chores, and may receive less food and clothing than the children of their new caregiver (M. Daniel, 2005; Madhavan, 2004; van Blerk & Ansell, 2007).

The nature of the kin relationship often affects the experience of the child. A study in Botswana found that when the new caregiver was the maternal grandmother, there was greater stability for the children who had lost parents, while when an aunt or uncle took

responsibility the children were more likely to have to migrate (and get used to living in a new place with new neighbours and friends) and they were more likely to suffer physical and psychosocial abuse (M. Daniel, 2005). Van Blerk & Ansell (2007) analyse the experiences of children moving to new homes in terms of the intergenerational contract. Parents invest in their children's education in the expectation that their children will care for them when they are no longer able to work. When HIV/AIDS removes the productive adults from the contract, other productive adults from the extended family have to step in and take on the responsibilities; the contract breaks down completely where the extended family is unable to meet the needs (van Blerk & Ansell, 2007, p. 870).

Orphaned children, in some cases, have no adult who is able to care for them or the adult caregiver is not able to provide adequate care and they live without an adult. Child-headed households (CHHs) may be defined as households headed by a person who is under 18 years of age (Hosegood et al., 2007, p. 331) and Luzze & Ssedyabule (2004) add that it should be recognised by the community as an independent household. Whether or not the AIDS epidemic is contributing to the phenomenon is contested in the literature with some contending that there is an increase in CHHs as a result of parental death and parallel impact on extended family (Evans, 2010; Kipp, Satzinger, Alibhai, & Rubaale, 2010; Luzze, 2002; Luzze & Ssedyabule, 2004) while other authors assert that there is no evidence of an increase in the incidence of CHHs (Hosegood, 2008; Hosegood, et al., 2007; Meintjes, Hall, Marera, & Boulle, 2010; Monasch & Boerma, 2004). Hosegood et al. (2008) point out that it is quantitative studies based on demographic surveys and census material that show low and unchanging incidence while qualitative studies focussed on CHHs find plenty of evidence of their existence. Luzze & Ssedyabule (2004) in a qualitative study of 969 CHHs in one district in Uganda, found that orphans living in CHHs are poorer than other orphans, have lower school attendance and poorer access to social services. Orphans who care for their siblings are no longer classed as children when they turn 18, even though no other circumstances have changed. Evans (2010) notes that rigorous application of age definitions does little to support young caregivers in need; she uses the more inclusive term "sibling-headed households" and describes how they often play down their 'adult' roles when negotiating assistance from NGOs or government agencies.

Institutional care is another alternative for orphans when the extended family is unable to meet their needs after the death of their parents. International organisations like UNICEF and UNAIDS, and western researchers view institutional care and orphanages as a last resort and the worst possible alternative. Sherr et al. (2008), for example, state that institutionalised children have poor outcomes and van Blerk & Ansell (2007) mention the inability of orphanages to meet the children's emotional (and sometimes physical) needs. Tolfree (2003) contends that the cost per child of providing institutional care is much greater than community care. In the "Framework for the protection, care and support of OVC living in a world with HIV and AIDS" which was the outcome of the first Global Partners' Forum convened by UNICEF in 2003, five key strategies are outlined (UNICEF, et al., 2004, p. 5). These strategies focus entirely on the family and community, institutions are not even mentioned. More recently the Joint Learning Initiative on Children and HIV/AIDS (JLICA) which concluded its work in 2009, based its learning groups largely on the "Framework" strategies (JLICA, 2011). Publications reflect the lack of interest in institutions, for example, when considering "evidence for changes in children's living and care arrangements" institutions are not even mentioned (Hosegood, 2008, p. 40). However, another JLICA report by Wakhweya et al. (2008, p. 19) describes the difficulty in finding literature on 'family

centred' care and they consider this might attributed to 'family' being a Western concept while the extended family or community is more the more usual focus in Africa. Whetten et al. (2009), in a study comparing institutional and community care of orphans and abandoned children in five countries (Ethiopia, Kenya, Tanzania, India & Cambodia) found that children in institutions were no worse off than those in the community in terms of health, emotional and cognitive functioning. They also found that "Many institutions grew out of the community to meet the need of caring for the new wave of orphans and are part of the community in a way that institutions in other regions [...] are not" (Whetten, et al., 2009, p. 9). In very poor communities extended family caregivers may not be able to provide adequate material care and orphans may be better off in institutions (Whetten, et al., 2009). A study in Botswana of a more traditional residential institution found that the children had access to increased resources such as "food security, decent shelter and uninterrupted education" although they felt disconnected to siblings, family and community (Morantz & Heymann, 2010, p. 14). Given the size and growth of the orphan challenge and the indications that the extended family is under stress, institutions should at least be considered; however residential care in Africa is an under-researched area.

2.2 Material well-being

Sickness reduces income earning capacity and ability to produce food leading to a fall in income and an increase in food insecurity. Once parents die, orphans are more likely than non-orphans to lack basic material needs, especially food security. This results in OVC being more likely to be malnourished than non-orphans (Watts et al., 2007).

Households caring for orphans have to spread resources between more people and may therefore experience lower levels of nutrition and health care and a lack of basic needs. A study in Botswana found that even where adults in the household were working, impoverishment increased when orphans were included in a household (Miller et al. 2006) and caregivers had to take unpaid leave from work to care for sick orphans (Heymann et al. 2007).

2.2.1 Access to essential services

Some studies have reported the unequivocal impact of orphanhood on education. Children whose parents were ill were more likely to experience increased absenteeism as they were needed at home for care duties, household chores and food production; as poverty increased, school fees could no longer be afforded and children were forced to drop out; the psychosocial impact of parental illness and death also had an impact on school performance often leading to failure, repetition and drop out (Badcock-Walters, 2002; Bicego et al. 2003; Mishra et al., 2007) . Other studies, however, have had ambivalent results; for example, Bennell (2005) found that there were minimal differences between enrolment rates of orphans and non-orphans, and that there was no correlation between differences in enrolment rates and HIV prevalence. This may be attributed to the introduction of free universal primary education as a result of the Millennium Goals campaign and also targeted aid to orphan households (Bennell, 2005, pp. 480-481). Birdthistle et al. (2009) found little difference between orphans and non-orphans in reasons for drop-out – financial reasons were the main cause for all, irrespective of status – but double orphans were found to have significantly greater absenteeism and lower attainment than non-orphans. However, they found that orphans face a disproportionate risk of acquiring sexual infections like HIV and herpes (Birdthistle, et al., 2009).

HIV/AIDS has had a direct impact on child mortality rates with a rise in infant and under five deaths across sub-Saharan Africa (Miller, 2007). The health of children affected by HIV/AIDS may be impacted in a number of ways. Children living with an ill parent will be more exposed to TB and other opportunistic infections associated with AIDS, orphaned children are more likely to suffer malnutrition and stunting and to have poorer access to health services (Giese, 2002; Miller, 2007). While Miller et al. (2007, p. 2482) found that "orphan status is a critical predictor of poor health", Kidman et al. (2010) - who examine the impact of AIDS in the family and community on child health in Malawi - found that for a range of physical health indicators orphaned children were no worse off than non-orphaned children but children living with ill parents were significantly more likely to suffer serious morbidity. In contrast, in a study in Zimbabwe, Watts et al. (2007) found that OVC were much more likely to suffer malnutrition and ill health than non-orphans and the difference could not be explained by differences in poverty. In the last five years or so, as a result of the introduction of NPAs (see section 2.2.2 below) the most vulnerable children are increasingly being given free access to health services (IATT, 2008).

2.2.2 Social protection

Social protection is "an agenda primarily for reducing vulnerability and risk of low-income households with regard to basic consumption and services" (Sabates Wheeler et al. 2009, p. 109) through 'safety nets' such as food grants or income transfers. In 2001, a year after the UN Millennium Declaration, 50 countries signed the UN General Assembly Special Session (UNGASS) *Declaration of Commitment on HIV/AIDS* agreeing to establish plans for OVC. In 2004, as mentioned above, UNICEF and the Global Partners' Forum established the "Framework for the protection, care and support of OVC living in a world with HIV and AIDS". The five key strategies outlined in the "Framework" form the foundation of the response to children affected by HIV/AIDS which underlie the National Plans of Action (NPAs) (Engle, 2008; Foster, 2008). On the initiative of USAID, UNICEF and UNAIDS, 17 high prevalence countries participated in Rapid Assessment Analysis and Action Planning (RAAAP) followed by NPAs to address the needs of children for basic services. While the exercise raised awareness of children's needs, it has been criticised as a donor-driven, 'emergency' exercise that has not necessarily been integrated into national planning (Engle, 2008). Some of the middle income countries in Southern Africa have social protection systems in place. South Africa for example, has cash transfers for families who care for orphans (IATT, 2008) as well as cash pensions for the elderly who are frequently caregivers to orphans. The Botswana Government provides monthly "food basket" to all registered orphans which often provides food for the whole household where the orphan is staying (M. Daniel, 2005). However, many sub-Saharan African countries are too poor to provide transfers in cash or kind, but since the establishment of NPAs some countries have implemented pilot projects targeting the poorest (IATT, 2008).

2.3 Psychosocial well-being

Children whose parents are very ill and children without parents do not suffer only physically, for example, from lack of basic needs, but they also experience grief at the loss of their parents, and may also have to face stigma and discrimination because of their parents HIV status. Recently the literature has started to explore the psychological impact on HIV/AIDS affected children (see for example Cluver et al., 2007; Cluver & Garner, 2007; Harms et al., 2009).

2.3.1 Cultural silence and children's grief

Cultural silence refers to the cultural taboos against speaking to children about death or about sex (Daniel, 2005; Mdleleni-Bookholane et al., 2004). HIV/AIDS, which in SSA is overwhelmingly spread through heterosexual transmission and which has had a huge impact on mortality rates, has inevitably put a spotlight on these sensitive issues. Many children in southern African countries have been prevented from attending the funerals of their parents, even if they wish to participate. There is a cultural understanding that death is too difficult and traumatic for children to cope with (Mdleleni-Bookholane, et al., 2004; Ndudani, 1998; Rantao, 2002). At an explicit level, culture is frequently used as an explanation for silence: "In our culture we do not talk to children about death, they are too young to understand" (Daniel, 2005, p. 28). Frequently children are not given an explanation about death and if they ask questions about their parents' death they sometimes do not receive answers or the reply does not help them understand the permanence of death, for example they might be told, "She has gone on a journey". Sometimes they are told they will understand when they are older (Daniel, 2005). In East Africa there is also cultural silence, but a different reason is given for not explaining death to children: it is believed that children do not understand and will not be affected by bereavement. Sengendo & Nambi (1997), in a study from Uganda, describe a cultural belief that children do not have emotional problems, while Snipstad et al. (2005, p. 191) in a study from Tanzania, report that adults believe children "have not got the brain yet" to comprehend death. Such beliefs limit children's opportunity to talk about their bereavement and deal with their grief.

Such cultural practices seek to protect children from the "pollution" of death (A. Richter & Müller, 2005, p. 1006) but they may also effectively marginalise "them from the process of grieving" (van der Heijden & Swartz, 2010, p. 45). Van der Heijden & Swartz (2010) stress that it is adults who impose this silence on children, adults reinforce cultural practices that compel children to silence concerning their grief. Cultural silence results in psychosocial problems for bereaved children. Children do understand that something is wrong and they worry about all sorts issues related to HIV/AIDS; such anxieties may hinder adaptive behaviour and the ability to solve problems (Snipstad, et al., 2005). Children also describe ruminating, "thinking too much", about a parent's death and how this can have a negative impact on their ability to concentrate in school with consequences for their attainment level (M. Daniel, 2005).

Only a very few programmes of psychosocial support exist which help children cope with grief and these will be discussed in section 2.4 below.

Another factor that reinforces cultural silence and blocks the processing of grief is AIDS-related stigma (van der Heijden & Swartz, 2010).

2.3.2 Stigma

Goffman (1963, p. 3) defines stigma as "an attribute that is deeply discrediting" and he continues "but it should be seen that the language of relationships, not attributes, is really needed." Frequently only the first part of this definition is quoted and Parker & Aggleton (2003, p. 14) note that this results in "highly individualised analyses" that focus on difference and negative attributes rather than exploring how stigma "devalues relationships". Stigma reinforces existing relations of power and control and perpetuates inequities (Parker & Aggleton, 2003). HIV/AIDS-related stigma is often linked to "immoral" (as judged by the dominant group) behaviour (sex and drug-use) and frequently leads to discrimination (Nyblade et al., 2003). Stigma can also be a reaction to fear of an incurable

disease (Ogden & Nyblade, 2005). Stigma and discrimination may manifest as verbal and physical abuse, neglect and isolation, for example, name-calling, separating utensils and denying access to services (Dlamini et al., 2007).

HIV/AIDS affected children experience stigma and discrimination related to HIV/AIDS-related illness and death of their parents. Stigma may exacerbate the effects of bereavement and hinder psychosocial adjustment (Deacon & Stephney, 2007; Makame & Grantham-Mcgregor, 2002). Within households, orphan children may be treated differently to the biological children of the caregiver, made to do more household chores, given less food, and punished more harshly (M. Daniel, 2005; Deacon & Stephney, 2007). They may be denied access to school if they lack full uniform and may experience stigmatising and discriminatory behaviour from other pupils and even from teachers (M. Daniel, 2005; Deacon & Stephney, 2007). Deacon & Stephney (2007, p. 34) also report that stigma affects children's access to health care, for example "health care workers refusing care, or providing inferior care, to children who were HIV positive". In a study on the stigmatisation of AIDS-affected children by other children, Campbell et al. (2010, p. 981) found that "children were often afraid to play with AIDS affected children [...] bullied and ostracised" them as well as stigmatising them through name-calling.

2.4 Responses to OVC

Local communities have responded to the needs of orphans in a range of ways – they may produce food for orphans or provide day care for infants so that older siblings can continue in school (M. Daniel, 2008). Responses are small-scale and disjointed, they often find it difficult to get funding beyond voluntary labour and have little influence on national-level responses to AIDS-affected children (Foster, 2008).

National governments have established National AIDS co-ordinating bodies under the 'Three Ones' agreement (one action framework, one AIDS co-ordinating body, and one country-level monitoring and evaluation system) (Foster, 2008, p. 23). Often programmes and policies to address children are only a small part of these larger programmes. Frequently the response is nominal and inadequate and it is left up to civil society to run programmes and the international institutions such as UNICEF to monitor and co-ordinate. However, civil society is often more aligned with external donors (such as the Global Fund and PEPFAR) than national structures, and international responses are often not in line with national strategies (Foster, 2008, pp. 24-25). Foster (2008, p. 23) terms this "alignment anarchism".

Wallis & Dukay (2009, p. 171) have described the evolution in the response to mass-orphaning as a move from emergency relief aid towards structural integration. Most externally funded programmes targeting orphans tend to provide material aid in the form of uniforms, school fees and food; but very few programmes offer grief counselling or psychosocial support. Material relief aid frequently comes with unintended side-effects like the undermining of social cohesion in the recipient communities, corruption and the exclusion of the most vulnerable (M. Daniel, 2008). Psychosocial support tends to be small-scale and NGO-based, but some regional scale programmes do exist. For example, an organisation called the Regional Psychosocial Support Initiative (REPSSI) is favoured by UNICEF and donors like the Swedish International Development Agency (SIDA). It works with local partners and has emerged as a leading provider of psychosocial services in 13 countries in southern and eastern Africa (Matikanya, James, & Maksud, 2006, p. 7). The "Memory Book" programme, originally developed in the UK to give psychosocial help to

immigrant orphans, has also had widespread application in southern and eastern Africa (Witter & Were, 2004).

While some governments provide relief assistance, such as the orphan grant in South Africa and the food basket for registered orphans in Botswana (Kallmann, 2003), it would seem that the Botswana government is the first government to become involved in scaled-up provision of *psychosocial* support to orphans. Since 2006, the Botswana government has been replicating (through 10 of the 16 Regional Councils) a retreat-based programme called “Ark for Children” developed in 2001 by a small local NGO, People and Nature Trust. The approach is culturally appropriate; it revives some customary practices such as age-set group formation as used to be practiced during initiation (M. L. Daniel & Thamuku, 2007). The emphasis in therapy is largely on group work which is effective in a collectivist society, while the use of individual therapy is limited though it effectively helps to breach deep-seated cultural silence.

3. Children infected by HIV

Many children infected at birth or through breast feeding do not survive beyond their second birthday. However increasing numbers of HIV positive children who do survive beyond infancy are now beginning to access anti-retroviral drugs.

3.1 Physical well-being: Illness, diagnosis and treatment

Giese (2002, p. 68) distinguishes between two groups of HIV positive children, namely rapid progressors, and slow progressors. Rapid progressors are “infants who become symptomatic and very sick within a few months of birth and usually die by the age of 2 years” while slow progressors “remain asymptomatic [...] during the first two years” and “generally survive to older childhood” (Giese, 2002, p. 68). Many children live with HIV until they are in early puberty before opportunistic infections begin to emerge. In some cases they are diagnosed with TB or another disease long before their HIV status is diagnosed.

A number of studies have examined the biomedical effects of illness and the implications of their status for their health and quality of life (Brown et al., 2000; Rao et al., 2007). Clinical manifestations of the disease include chronic cough, fevers, nausea and diarrhoea as well as chronic dermatological conditions such as rashes, fungal infections and abscesses (O'Hare et al., 2005). Those on ART may suffer side effects such as rashes, itching all over, a burning sensation in the legs and nausea. If they lack good nutrition they may experience difficulty in swallowing the drugs, nausea and vomiting, sweating and general weakness. Numerous studies have examined factors influencing adherence to ART among children (Bikaako-Kajura et al., 2006; Davies et al., 2008; Polisset et al., 2009; van Griensven et al., 2008; Van Wingham et al., 2008; Vreeman et al., 2008); issues include disclosure, relationship with caregiver, the involvement of health workers and structural issues like poverty.

Studies report that few children are informed of their HIV status and when they are informed, the event is controlled by their caregivers or by health care professionals (Lesch et al., 2007; Vaz et al., 2008). The most frequently given reasons for non-disclosure by caregivers include the associated stigma and discrimination, fear that the child will be unable to keep the secret, parental guilt, and concerns for the child's emotional and mental health, (Brown, et al., 2000; Hejoaka, 2009; Lesch, et al., 2007; Siripong et al., 2007; Vaz, et al., 2008) while disclosure usually occurs because of the need for the child to understand and

adhere to their treatment (Brown, et al., 2000; Lesch et al., 2007; Vaz et al., 2008). Disclosure in a way that is appropriate to the child's cognitive development has been found to improve the child's psychological adjustment (Brown, et al., 2000; Lwin & Melvin, 2001).

Access to ART most frequently occurs through NGOs or FBOs rather than through government provided services. In such organisations the children are more likely to receive appropriate counselling and psychosocial support.

3.2 Psychosocial well-being: Secrecy and stigma

The psychosocial experiences of children affected by AIDS have been explored in several studies (Cluver & Gardner, 2007b; Fjermestad et al., 2008; Foster, 2002; Skovdal, 2009), but little research has been done on the psychosocial aspects of the lives of children infected by HIV/AIDS. Many HIV positive children will experience the sickness and, in some cases, the death of their mother and/or their father. Multiple losses may affect the child psychologically, particularly if there is no one to support them in their bereavement (Rao, et al., 2007) or to answer their questions. Secrecy and cultural silence may stimulate feelings of shame and guilt in a child (Brown, et al., 2000; M. Daniel, 2005; Wood, Chase, & Aggleton, 2006). Brown et al. (2000) contend that children more readily adjust to living with HIV when the parent's or caregiver's response is optimistic and this enables them to overcome disease and disability factors. If the mother (or caregiver) is coping well, the child is more likely to respond positively (L. Richter, 2002).

Children living with HIV often have physical symptoms of disease. Even when they start on ART they may have rashes or other visible signs particularly when the dosage is wrong or needs adjusting. This makes it easy for the child to be stigmatised and discriminated against. In addition, the centres where they receive treatment are often associated with HIV/AIDS and a child seen coming and going from such a centre may also be stigmatised. The caregivers of children living with HIV almost always impose secrecy on the child about his/her status. Mothers who are living with HIV feel enormous shame and want their child to keep the secret. This may be extremely difficult when medications have to be taken regularly twice a day and when there are physical symptoms. Children usually comply.

Secrecy involves concealment, either by hiding something from the view or attention of others or by keeping silent about it. In the case of HIV, that which is concealed includes status, ongoing treatment, receipt of medical and material aid and visits to the treatment centre (Hardon et al., 2007). Where children's HIV status is involved, mothers may keep the status secret from the child or co-opt the child into keeping their status secret. Hejoaka (2009, p. 870), in her study on care and secrecy, explores the way in which mothers manage the "tensions between disclosure and concealment" of the HIV status of their children. Mothers have strategies to limit access to their homes but concealment is much harder outside the domestic space, especially when regular hospital visits are required. Mothers hesitated to disclose to their children for fear they would not be able to keep the secret, but where children *were* told, they followed their mother's lead in concealment (Hejoaka, 2009). The issue of secrecy is more about *naming* than about *knowing*: even when children have not been told, they know something is wrong (Nagler et al., 1995). Once children have the name, they do not necessarily use it, most children will keep the secret as their caregivers and society have taught them (Daniel et al., 2007; Nagler et al., 1995).

What compels to secrecy those who are infected, is the attitudes, beliefs and actions of others in society (Hardon, et al., 2007). Direct stigmatisation and discrimination against some HIV positive people, for example through labelling or exclusion, raises the *fear of stigma* among

many others who have not necessarily had severe or direct experience of being stigmatised. This fear of stigma then leads to HIV-affected people adopting coping strategies of secrecy and silence (Ruora, et al., 2009). Shame, another direct cause for secrecy (Duffy, 2005), has its roots in the culture of blame - blame for breaching morality - which is frequently attributed to women (LeClerc-Madlala, 2001). LeClerc-Madlala (2001: 45) contends that this process of blaming women "both reflects and contributes to women's already marginalised and subordinate status in society". The underlying causes of shame are power relations, culture and morality. Cultural norms may be at the root of blame-related stigma and shame when HIV/AIDS is associated with immoral and avoidable behaviour (LeClerc-Madlala, 2001; Ruora, et al., 2009). Social constraints lead to isolation and the secrecy adopted for fear of stigma hinders care (Hejoaka, 2009).

Silence deprives HIV positive children of potential help as they cannot ask neighbours for support without disclosing the reason why. Smith et al. (2008, p. 1268), whose study concerns adults rather than children, note the strong relationship between social support and public openness about HIV status: "people cannot actually receive social support until disclosure occurs. On the other hand, individuals must perceive social support will exist before they make the decision to disclose." Smith et al. (2008) link the fear of stigma-related rejection to limited social networks and low self-esteem; and several studies note that keeping a secret increases stress and anxiety (Duffy, 2005; Smith, et al., 2008). Menon et al (2007: 349) conclude that "interventions to promote disclosure could facilitate access to emotional and peer support". Shame is frequently associated with blame which implies a moral judgement situating the underlying cause within society's culture and morality. Blystad & Moland (2009) show that feelings of guilt and shame lead to isolation, marginalisation, uncertainty and adversity for mothers of HIV positive children, limiting the social support they so desperately need. In order to support and include mothers of HIV positive children it is these underlying causes that should be tackled. Secrecy and silence are the products of shame and the fear of stigma. Both secrecy and silence worsen the experiences of HIV positive children and add to their adversities. Providing ART to HIV positive children is a start and should be seen as part of a much larger process.

4. Conclusion

Children in sub-Saharan Africa are disproportionately affected and infected by HIV/AIDS. Many of them experience physical deprivation such as a lack of basic needs, social disruption when they have to change their living situation and they face psychosocial challenges, particularly cultural silence and stigma. Local, national and international efforts have made some progress in reducing the physical vulnerability of children affected by HIV/AIDS for example by providing food and school uniforms; they have also made progress in providing access to ART for children infected by HIV/AIDS. However, in terms of psychosocial support, particularly in tackling stigma, there is still much to be done.

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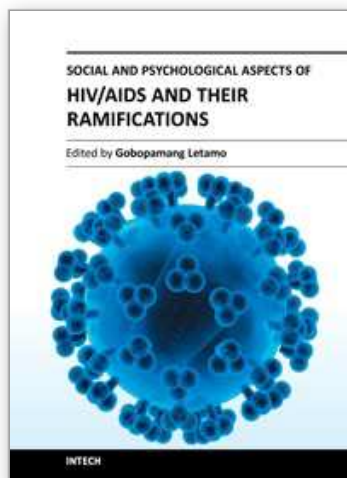
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This book has assembled an array of chapters on the social and psychosocial aspects of HIV/AIDS and their impact on HIV/AIDS and related behaviours. The book addresses key areas of HIV and AIDS, including, but not in any way limited to, care-seeking behaviour, adherence, access, psychosocial needs and support services, discrimination and the impact the epidemic has on various sectors of the economy. The book has seventeen chapters; seven chapters deal with social aspects of HIV/AIDS, four with psychosocial aspects of HIV/AIDS, and the remaining six chapters with the impact of social and psychosocial factors on HIV/AIDS and related behaviours. The book is an essential reading for academics, students and other people interested in the field of HIV and AIDS.

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